MICRO *AD HOC* HEALTH SOCIAL NETWORKS (uHSN): DESIGN AND EVALUATION OF A SOCIAL-BASED SOLUTION FOR PATIENT SUPPORT

ABSTRACT

Objective: To contribute the design, development, and assessment of a new concept: Micro *ad hoc* Health Social Networks (uHSN), to create a social-based solution for supporting patients with chronic disease.

Design: After in-depth fieldwork and intensive co-design over a 4-year project following Community-Based Participatory Research (CBPR), this paper contributes a new paradigm of uHSN, defining two interaction areas (the "backstage", the sphere invisible to the final user, where processes that build services take place; and the "onstage", the visible part that includes the patients and relatives), and describes a new transversal concept, i.e., "network spaces segments," to provide timely interaction among all involved profiles and guaranteeing qualitative relationships. This proposal is applicable to any service design project and to all types of work areas; in the present work, it served as a social-based solution for supporting patients with chronic disease in two real-life health scenarios: a Parkinson disease patient association and a Stroke rehabilitation service in a hospital. These two scenarios included the following main features: thematic (related to the specific disease), private, and secure (only for the patient, relatives, healthcare professional, therapist, carer), with defined specific objectives (around patient support), small size (from tens to hundreds of users), ability to integrate innovative services (e.g., connection to hospital information service or to health sensors), supported by local therapeutic associations, and clustered with preconfigured relationships among users based in network groups.

Measurements: Using a mixed qualitative and quantitative approach for 6 months, the performance of the uHSN was assessed in the two environments: a hospital rehabilitation unit working with Stroke patients, and a Parkinson disease association providing physiotherapy, occupational therapy, psychological support, speech therapy, and social services. We describe the proposed methods for evaluating the uHSN quantitatively and qualitatively, and how the scientific community can replicate and/or integrate this contribution in its research.

Results: The uHSN overcomes the main limitations of traditional HSNs in the main areas recommended in the literature: privacy, security, transparency, system ecology, Quality of Service (QoS), and technology enhancement. The qualitative and quantitative research demonstrated its viability and replicability in four key points: user acceptance, productivity improvement, QoS enhancement, and fostering of social relations. It also meets the expectation of connecting health and social worlds, supporting distance rehabilitation, improving professionals' efficiency, expanding users' social capital, improving information quality and immediacy, and enhancing perceived peer/social/emotional support. The scientific contributions of the present paper are the first step not only in customizing health solutions that empower patients, their families, and healthcare professionals, but also in transferring this new paradigm to other scientific, professional, and social environments to create new opportunities.

INTRODUCTION

Humans are more or less social depending on personal circumstances; numerous studies have demonstrated the health and subjective well-being benefits of having a strong and active social network.[1-3] In the era of instant communication, this can be extended to the virtual world, and thus, participation in Online Social Networks (OSN) also has the same effect.[4,5]

Health problems, especially chronic diseases, are a circumstance that usually change how a person relates to others,[6,7] influencing their social capital.[8] From these new needs, and because clinicians are becoming more involved in social media,[9] there are many OSNs dedicated to health that have actual impact on patients.[10] These Health Social Networks (HSN) can be thematic (e.g., Acor.org, Stupidcancer.org, RareShare.org), sometimes using broad public [11] (e.g., Facebook or Twitter) or generalist (e.g., Medhelp.org, Curetogether.com, Patientslikeme.com) OSN platforms. In any case, they usually share similar objectives and benefits, behaving as: a point of contact between patients and health professionals, a data collection resource for companies and/or researchers, a tool for patient tracking and rehabilitation, a means of increasing interaction with others, an instrument for creating awareness and prevention, a source of health information, and public health surveillance with the potential to influence health policies, among other implications. Many reviews in the literature have analyzed the existing HSNs: Moorhead [12] concludes that the main identified benefits are: increased interactions with others that could fulfill practical and emotional needs; more available, shared, and tailored information; increased accessibility and wider access to health information; peer/social/emotional support; public health surveillance; and the potential to influence health policy. Such studies have also targeted a number of HSN limitations and unmet needs, which are summarized below and grouped by six areas recommended in the literature (**Table 1**):

- ***Privacy, security, and transparency***. HSNs are vulnerable to risks arising from sharing information online and their consequences for confidentiality and privacy, such as: low accessibility of privacy policies, communication and control of privacy risks, lack of user control over personal data-sharing, risks of centralized sharing of user data, lack of user education in maintaining confidentiality and privacy, and lack of information on the use of credentialed moderators. Furthermore, the openness and transparency of HSNs, especially in relation to commercial content and commercial users, is not guaranteed.
- ***Validity assessment***. Traditionally, HSNs have limitations on conducting controlled trials to determine their relative effectiveness and longer-term impact on: supporting the patient–health professional relationship; enhancing general public, patient, and health professional interpersonal communication; leading to behavior changes for healthy lifestyles; and evaluating the impact of online support interventions.
- ***Design methodologies***. User empowerment, design features, interactivity, and awareness of social context are needed in the informatics systems designed for patients, their families, and their communities. Furthermore, social media has limited impact for health communication in population groups with special needs (minority groups, patient groups, culture differences), and it is difficult to find facilitators for a self-managed health website.
- ***System ecology***. It is necessary to engage key stakeholders (to balance autonomy, community ownership, conditions for innovation, and consumer protection), target community-wide outcomes and participation of local community groups (they can play a key role as partners or facilitators in online support systems and integrate existing community-based psychosocial programs), employ ecological systems theory and the principles of Community-Based Participatory Research (CBPR), address the interdependence between online and real-world support (recognizing the role that online communication can play in real-

world interactions, and vice versa), and address a person's existing social networks (e.g., family, friends, co-workers).

- ***Quality of Service (QoS)***. HSNs need a patient-centered perspective in presenting content and information to guarantee timely and personalized care. It would be convenient to conduct periodic external reviews of member discussions to avoid misinformation, providing effective moderation support. Furthermore, the veracity of the information is essential to ensure that the contents correspond with the professional recommendations.
- ***Technology enhancement***. HSNs may be used in a synergistic manner with personal health records, smart devices, and through more sophisticated and emerging interactive tools.

Table 1. HSN limitations and unmet needs

Area	HSN limitations and unmet needs	References
Privacy, security and transparency	Risks from sharing information online without guarantees of confidentiality and privacy Lack of user control and detailed information on credentialed moderators Need for openness and transparency both in commercial content and commercial users	Moorhead,[12] Orizio,[13] Li,[14] Weitzman,[15] Al-Kadi.[16]
Validity assessment	Need for controlled trials to determine effectiveness and longer-term impact	Moorhead,[12] Weiss.[17]
Design methodologies	Need for user empowerment, interactivity, and awareness of social context	Weiss,[17] Orizio,[13] Nambisan,[18] Huang,[19] Al-Kadi.[16]
	Limited impact of social media for health communication in special needs population	Moorhead,[12] Nambisan.[18]
	Barriers to using a self-management health website	Yu.[20]
System ecology	Need to engage key stakeholders to balance autonomy and community ownership	Weitzman.[15]
	Need for target community-wide outcomes and local community group participation	Weiss.[17]
	Need to employ ecological systems theory and CBPR	Weiss.[17]
	Need to address the interdependence between online support and real-world support	Wellman.[21]
	Need to address a person's existing social networks	Weiss.[17]
Quality of Service (QoS)	Lack of patient-centered perspective in presenting content and information	Yu.[20]
	Need to enlist periodic external review of samples of member discussions	Weitzman,[15] Al-Kadi.[16]
	Lack of truthful information and timely and personalized care	Yu.[20]
	Alignment of content with science and professional practice recommendations	Weitzman.[15]
Technology enhancement	Need for integration with personal health records and mobile devices	Laranjo,[10] Al-Kadi.[16]
	Need for the development of more sophisticated and emerging interactive tools	Huang.[19]

The objective of this work is to translate these limitations and unmet needs into challenges by contributing the design, development, and assessment of a new concept: a micro *ad hoc* HSN (uHSN), to create a social-based solution for (in this case) supporting patients with chronic diseases. *Background* and *Materials and Methods* sections detail the research carried out in the design process of the proposed methodology, how the uHSN was evaluated, what quantitative and qualitative measures were obtained, and finally, how it was tested for use in practice and was replicated by the scientific community in its research. *Results* section reports in-depth analysis of the obtained results from quantitative, descriptive, and interpretative perspectives. Finally, *Discussion* section contains a critical discussion that supports our conclusions and proposes further studies.

BACKGROUND. Design and implementation

From the challenges posed above, we formulated the following design criteria:

- ***Privacy, security, and transparency:*** to ensure the security of personal information, including specific modules of privacy, confidentiality, transparency, and authentication.
- ***Validity assessment:*** to create an entire validation methodology prior to the implementation stage to guarantee user needs, and encompass all user profiles.
- ***Design methodologies:*** to focus on user empowerment (in this case, giving particular thought to special needs population groups) with awareness of social context, enhancing interactivity and self-management.
- ***System ecology:*** to build an architecture that includes all involved profiles with their contexts and relationships.
- ***QoS:*** to incorporate mechanisms for timely and personalized care, guaranteeing truthful information through scientific validation by users with specialist profiles.
- ***Technology enhancement:*** to integrate software modules that allow the implementation of all the proposals into multi-platform solutions compatible with smart devices, interactive tools, and health information systems.

The first approach to consider when developing the uHSN was to work with an existing social network, such as Facebook or Google Plus.[11] However, according to our design criteria, this was not suitable, as it involved remarkable limitations related to the connection of hardware devices, permissions, functionality limitations, privacy, and accessibility.

Thus, fulfilling the previously proposed design criteria, the uHSN (**Figure 1**) was supported on a plugin-based architecture by *Elgg* platform. It follows a Model-View-Controller (MVC) pattern and allows the development of custom plug-ins and the application of a Graphical User Interface (GUI) using Cascading Style Sheets (CSS) markup. These decisions were justified because *Elgg* platform includes specific modules to provide many of the raised functionalities, such as: confidentiality, transparency, and authentication modules to guarantee privacy; messaging, blog, and discussion modules to guarantee user empowerment and interactive relationships among profiles; and validation and multi-user modules to guarantee truthful information. In addition, *Elgg* architecture allows the easy development and integration of custom modules to create new, self-developed functionalities. Indeed, *Elgg* platform hosts a rich development community, which provides additional modules that can be used to extend the uHSN functionalities.

Furthermore, this technological proposal is innovative and fully compatible with smart devices, interactive tools, and Health Information Systems (HIS), as shown in the following modules (**Figure 1**): a Health Level 7 (HL7) module, which allows the exchange of HL7 messages with external entities through the Mirth Connect middleware and Electronic Health Record (EHR) access;[22] a Sharable Content Object Reference Model (SCORM) module, which allows access to SCORM courses on the SCORM Cloud online learning platform;[23] a Devices module, which allows data registration from user monitoring devices, such as the Zephyr heart rate monitor;[24] and a Treatments module, which allows the definition and assignation of custom therapies to users, among others. In addition, the proposed *Elgg* platform provides a Representational State Transfer (REST)-based web service Application Programming Interface (API), which allows external third-party agents to access the platform and specifically facilitates the monitoring devices connector and a memory-like game used in some therapies. Moreover, the visual style of the platform uses a Responsive Design approach,[25] which ensures proper visualization on devices of any size.

The novelty of the technology involved, and the lack of references in this area, warranted this proposed flexible design process. Furthermore, we faced the challenge of designing an *ad hoc* interaction map and GUI, and finally developing our own system platform. **Figure 2** represents the stakeholders included as users, distributed in two conceptual interaction areas: the "backstage" (the sphere invisible to the final user, where the processes that build services take place) and the "onstage" (the visible part that includes the patients and relatives). Inside these two interaction areas and transverse to them, eight network spaces segmenting specific groups of interaction with different objectives and subjects were considered. These network spaces are based on the interaction groups in the real world—in line with the recommendations of Weiss et al.—[17] and extend to providing the benefit of Information and Communication Technologies (ICT); they also constitute the central concept of community, an *ad hoc* methodology oriented to uHSN design.

Each of these network spaces is implemented in the uHSN through a group, which behaves as a restricted access area, and content related to the network space is available only to the members of said group. **Figure 3** shows an example with three proposed groups: direct attention of a patient (in this case, the fictitious "Paco"), direct care professionals, and all patients. For any group, an administrator should be selected, and be responsible for deciding which users can access each group (the groups can be public or open to join for any user) and for defining which uHSN components are enabled for each group (thus, generated content will be accessible only to members of the group). Some of these components can also be used outside the context of any group, and the user can define the access level (private, only friends, or public) for the related content. For example, a patient can upload some images and share them with friends. Other components, such as messaging or the user profile, are not related with groups but with the users directly.

Another important aspect of the platform that differs from mainstream uHSNs is profile customization. The uHSN functionality depends on the user profile (e.g., a therapist can define and assign therapies, whereas patients can only see the therapies assigned to them). Thus, we developed a customized module to determine what platform components are presented to each user according to their profile, mostly overriding the *Elgg* default view-generation mechanisms.

Finally, it is important to highlight two contributions. First, this proposed project methodology, platform architecture, and design of network spaces is an open contribution to the scientific community for replication in its research studies, with the required adaptation to every health context, even in environments with highly heterogeneous profiles. Furthermore, with a suitable data-mining process, every platform module allows the measurement of diverse qualitative and quantitative data, such as the number of images updated, viewing frequency and user profiles, the inter-relationships among these profiles, and the messages and discussions generated. An example of these data of interest is analysis of the interaction level (relational, content-driven, etc.) between profiles.

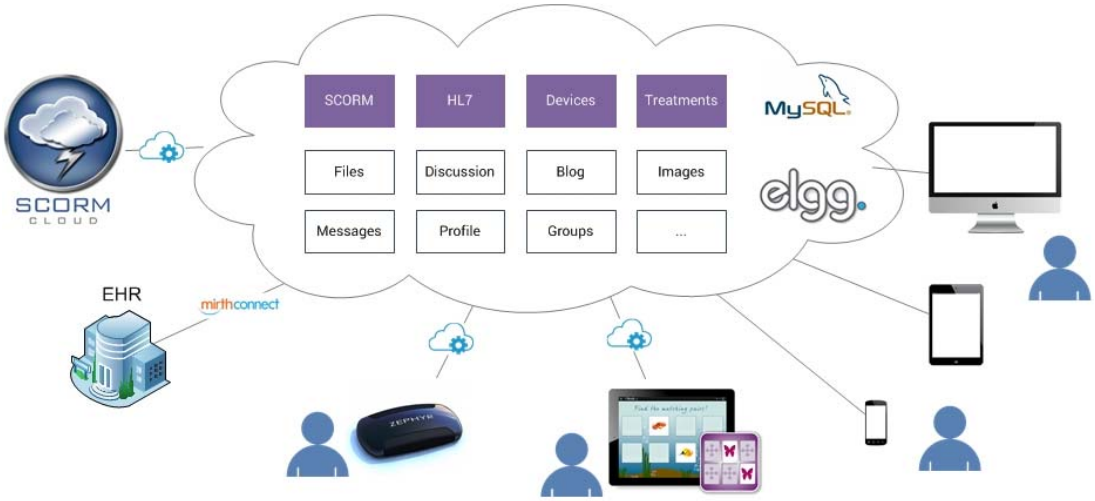
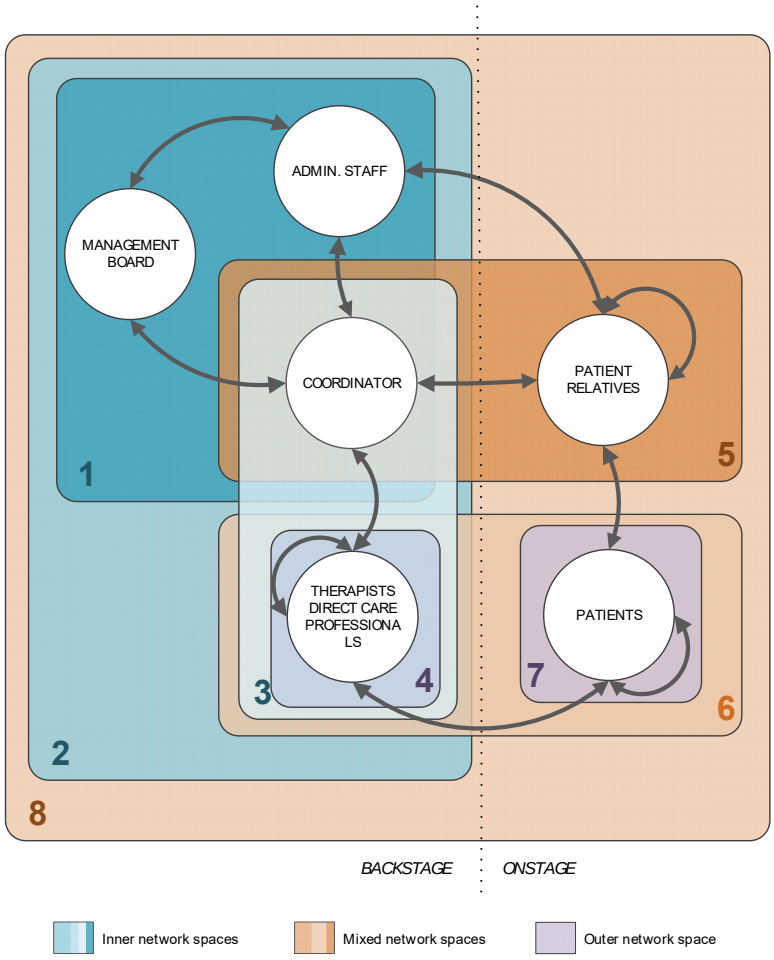


Figure 1. uHSN platform architecture.



#	NETWORK SPACE	ROLE
1	**Coordination**	Discuss strategy and organizational issues
2	**Organization**	Coordination of association procedures (workplans, holyday plans, organizational updates, etc.)
3	**Direct attention management**	Design of patient's attention plans, patient organization and tracking, etc.
4	**Departments**	Some therapists have specific specialties such as psychology, occupational therapy, physiotherapy, etc. This group is mainly used to design specific therapies.
5	**Patient's relatives**	N private groups for each patient with limited cognitive capacities, where coordinators inform relatives about health issues, periodic reports, etc. Also, relatives inform about medication changes and other relevant issues
6	**Direct attention execution**	N private groups for each patient without limited cognitive capacities, where therapists provide periodic reports, send homework, etc. Also, patients inform about medication issues and other health-related questions.
7	**Patients**	Private group similar to facebook (but private), where patients share personal information and pictures.
8	**Association**	Inform all associates about events, publish pictures from events, provide a discussion channel, provide notices, etc.

Figure 2. Design of network spaces for uHSNs.

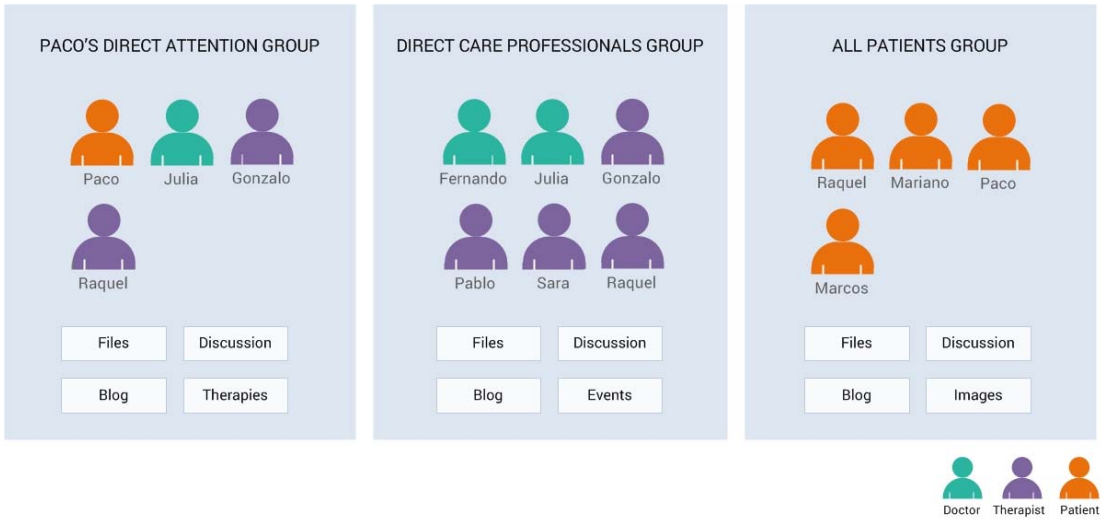


Figure 3. Implementation of network spaces.

MATERIALS AND METHODS

From the previously proposed design criteria, the present work initially followed a strategy built in CBPR to achieve the uHSN paradigm. This methodology is specifically recommended for designing, implementing, and evaluating social support in online communities, networks, and groups.[13][40] Additionally, due to the complexity of profiles and relationships, we used a set of user-oriented methodologies such as Cultural Probes,[14] Personas,[15] Blueprint,[16], and Wizard of Oz.[17] The project ecosystem included interdisciplinary professional profiles (designer, developer, social/health professionals, end users, etc.) working within scenarios of high user profile heterogeneity, and the complex relationships among them: patients, relatives, carers, therapists, etc.

Figure 4 illustrates how the iterative, participatory, and action-oriented principles were developed, to demonstrate their applicability to all types of x-disciplinary (as an open concept that can include any possible level of multi-, inter-, cross- and trans- disciplinarity) [41] teams, and their extrapolation to very diverse ecosystems. The project cycles are divided into four stages with different objectives and work team composition: (a) *identification of needs* includes all technical and user profiles and aims to identify initial requirements and restrictions; (b) *concept design* includes all user profiles to obtain product specifications and first prototypes whose main concepts are initially evaluated; (c) *development* includes only designer and developer profiles, from validated product specifications to consolidated prototypes; and (d) *evaluation* first includes all user profiles to assess the design technically; second, it includes end user and professional profiles to confirm the entire solution with certainty.

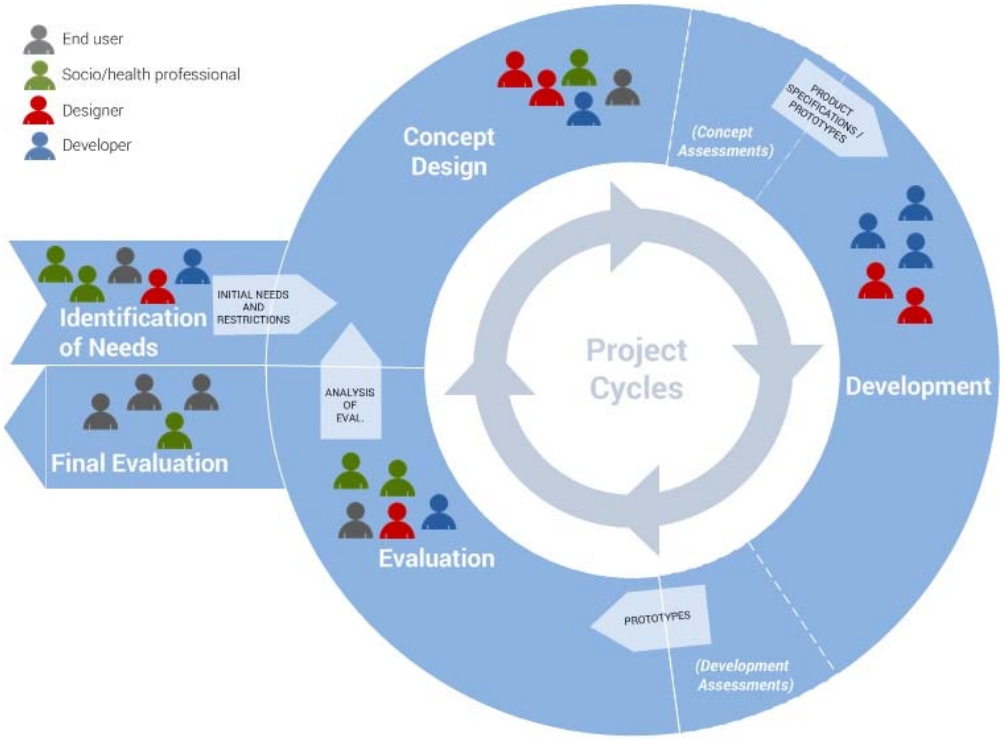


Figure 4. Project methodology and community organization.

From this conceptual scope, the specific contributions presented in the present paper are the result of the assessment of the proposed uHSN (in the final step of the iterative design process, namely "Final Evaluation" in **Figure 4**) in two health communities related to Parkinson disease and Stroke. The former was coordinated by a university, and involved three departments (computing, design, sociology), a Parkinson patient association involving five professional profiles (occupational therapist, psychologist, physiotherapist, speech therapist, social worker), and a software company that contributed a customized development in this scenario. The Stroke community was connected to a hospital involving clinicians, therapists, and technical staff, a second university, and two companies that worked on customized development and design tasks.

Every health community shared a general assessment design according to the *Xassess* evaluation framework,[30] articulated as multiple case studies and carried out in a CBPR. *Xassess* has several advantages, e.g., it has a structured reference framework that is sufficiently flexible to allow tool and strategy adaptations for each scenario; it also has generic tools for establishing a common ground and for guiding professionals who are not experts in evaluation. Furthermore, both communities shared a universal team of software developers to provide communities with unlimited use of the uHSN during the assessment.

The present work contributes the design of a balanced evaluation, including some methods that cover three key aspects: (a) to consider a multi-referential and integrated perspective (patients, carers, relatives, professionals); (b) to fit the nature of key information (indicators); and (c) to assess four main objectives: user acceptance of the uHSN, productivity improvement, QoS enhancement, and the fostering of social relations. **Table 2** shows the indicators, methods, and findings associated with every assessment objective.

Table 2. Assessment design for uHSN

Assessment objective	Indicator	Method	Finding
User acceptance of the uHSN	Use of uHSN and content created	Data log	Fig. 5
	uHSN accessibility and usability		Figs. 6-7
	uHSN content use		Fig. 8
	Effort needed to learn to use the uHSN	Surveys, interviews and focus groups	Questions 1-5
	Usability of the uHSN		
	User attitudes towards uHSN and emergent issues		
Productivity improvement	User interaction through uHSN messaging	Data log	Fig. 9
	Use of paper	Surveys and interviews	Questions 6-8
	Administration time required to attend to staff issues		
	Health professionals' time devoted to using the uHSN		
QoS enhancement	Improvement of communication among users	Surveys, interviews and focus groups	Questions 9-23
	New communication channels for the community		
	Improved patient medication management		
	Improved management of patient history		
	Increased rate of remote therapies followed per patient		
	New discussion channels for preparing patient intervention		
	Emergent issues: innovative activities		
Fostering of social relations	Community social activity (forums, groups, comments, etc.)	Data log	Fig. 10
	Enhancement of social circles: patient-professional	Surveys, interviews and focus groups	Questions 24-37
	Enhancement of social circles: patient-patient		
	Enhancement of social circles: professional-professional		
	Emergent issues: external activities among staff members		

For each method used, our approach was adapted to the indicator and the strategy of combination with other methods, taking into account: the user profile's feasibility, applicability, and adaptation to each specific scenario, and the objective(s) of evaluation. Following the use of *Xassess*, we determined the key evaluation

factors: purpose and objectives, agents and scenarios, and methodological approach (combination, triangulation, or complementation) for each indicator; for each indicator, we assessed the singular demands of each user profile, and budget, time, and personnel constraints, and we ensured that each evaluation dimension was covered under the combination of quantitative and qualitative methods, providing different perspectives of the same reality:

- ***Data logs*** provided information on two levels: Raw data analysis of 17,300 log records that segmented data according profile, type, categories, and user relationship by matching the cross-relations, using visual and interpretable trends to provide quantitative information on who (professionals or patients), when, and for what (medical treatment, videos, blog, messaging) the uHSN was used. On another level, and as a complement of quantitative data, a content analysis was carried out under the lens of ethnographic research, and confirmed real and meaningful use, and effective user interaction.
- ***Surveys*** included several closed and open items (extending the work by Nambisian[18]) and Likert scales to obtain perceptions in the four assessment objectives:

  1. **User acceptance of the uHSN** (questions 1-5): *How often did I use the platform? How complicated has the learning about how to use the platform been? How did I liked the documentation for the platform? How did I like the visual/functional design of the platform? How would I define the different functions of the platform?* The first three questions are direct references, while the last two are indirect questions of a more qualitative nature; in this case, the objective was to triangulate the results of both blocks with the aim of reducing effects such as Hawthorne Effect.[42] [43]
  2. **Productivity improvement** (questions 6-8): *How often did I use messaging to communicate with patients? How much time did I use for social health issues? and for platform administration?*
  3. **QoS enhancement** (questions 9-23):

     [for patients] *Did the platform improve the quality of the information I have about my illness? Was the information I obtained credible? Was the information I obtained relevant? Did I obtain the information I needed quickly? Did the platform improve the management of my medication? Did the platform ease the performance of therapies at home? Did the platform establish new communication channels between me and professionals?*

     [for professionals] *Did the platform improve the management of the patient's history? Did the platform establish new discussion channels to discuss patient intervention? Did the platform improve the management of patient medication? Was the information I obtained credible? Was the information I obtained relevant? Did I obtain the information I needed quickly? Did the platform establish new communication channels between me and patients? Did the platform increase the performance of patient therapies at home?*
  4. **Fostering of social relations** (questions 24-37): *How often did I exchange messages with other patients? How often did I participate in the forum, contribute to image galleries, or leave comments? Do I believe that private forums, discussion groups, image galleries are positive for me? How do I feel about the relationship between patients and professionals? Do I think that having forums, discussion groups, image galleries, etc. with professionals improves their attention / our relationship? How do I feel about the relationship with other people in my situation? How do I empathize with other members of the community? Do I think that the other members of the community were sincere? Would I be willing to provide support (emotional/social) to other users? Did I find users with whom I could share joys and sorrows? Did I talk about my problems with the disease with other users? Did the members of this community behave like me, think like me, or have a health situation similar to mine?*

- ***Interviews and focus groups*** were conducted by the same experienced researcher, following a two main block structure: a general phase (equivalent for all user profiles), followed by individual discussions on the specific topics of every user profile. The interviews and focus groups were interrelated: the focus groups were carried out and analyzed first, subsequently specific participants were selected to attend in-depth interviews on certain aspects. The criterion for the interview selection was the communicative and critical capacity the participants had demonstrated in the focus groups, with slight nuances in the professional profile, where selection was largely determined by their availability in terms of time. All interactions were recorded and later analyzed by two researchers with expertise in health and user interaction (a behavioral sociologist specialized in health projects and a Human-Computer Interaction (HCI) specialist with ethnographic methodologies expertise) to build consensus on two key stages: (a) initial narratives to share anecdotes and experiences about the use and adoption of uHSN with the community; and (b) explanations and details of the more relevant key issues to remark on the functionalities, utilities, milestones, and positive changes the uHSN contributes to each user profile. The individual discussions differentiated between patients and health professionals. For patients, the interviews included questions and comments such as: *What have you missed in the platform? Any fear or concern?* to obtain specific information about their privacy, confidentiality, and integrity, among other topics of interest. For health professionals, the interviews included questions and comments such as: *The most difficult task you have found on the platform has been... For mass use of the platform, it is necessary...* to obtain specific information on obstacles/resistances, productivity impact, efficiency, and efficacy, among other topics of interest.

The project's complexity and the different scenario locations clearly influenced the method selection, as some experiments would not be performed by the same person, and the evaluators had differing expertise. Therefore, the criterion was to select more traditional elimination methods, where all evaluators would have previous experience. To understand the methods selection, it is also important to consider the character of "final evaluation," which had been preceded by other product evaluations in previous iterations. In these intermediate evaluations, the selected methods combined assessment with that of innovation, and were more open to emerging issues. In this case, the methods focused more on validating the usefulness of evaluation as a validation and contribution tool. For example, past iterations qualitatively evaluated usability with prototypes using the Wizard of Oz method;[17] evaluators were required to undergo a training course, and we constructed a specific follow-up of the interpretations and results. In the case presented here, i.e., the final evaluation, usability was validated with the mixed-methods approach but with a more concise or quantitative approach, providing more in-depth survey results through the interviews, but with certainty, as provided by the results of the most recent prototypes designed and redesigned in the prior iterations.

RESULTS

In the present study, we focused on two health communities –Parkinson and Stroke– with different idiosyncrasies (Parkinson is patient association with therapeutic services that patients usually enroll for life, while Stroke is hospital-based and work with patients for short-medium term), professionals and patient profiles (ages and cognitive capacities). Based on the main assessment objectives described in the *Materials and Methods* section, **Table 3** presents the key conclusions of the assessments, detailed according to each indicator.

Table 3. Comparative assessments in the two health communities

	Health community	
	Parkinson	**Stroke**
Location	A patient association	Rehabilitation section of a hospital
User profiles	8 patients and 5 professionals (2 physiotherapists, 2 speech therapist and 1 psychologist)	6 patients, 5 relatives and 2 professionals (1 physiotherapist and 1 computer technician)
Duration	6-month experimental pilot project, followed by activities and workshops about uHSN organized by professionals and addressed to patients	40 days into an experimental pilot project context
Data log	11,500 log reports, 203 messages, 79 assigned medical treatments, 56 performed medical treatments, 44 exchanged files, 35 exchanged images, 10 exchanged videos, 19 created blogs, 14 posted events and 4 discussion chats	5800 log reports, 18 messages, 5 assigned medical treatments, 5 performed medical treatments, 11 exchanged files, 3 exchanged images, 11 exchanged videos, 1 created blogs, 6 posted events and 2 discussion chats
Surveys, interviews and focus groups	39 surveys, 26 interviews and 3 focus groups for transverse selection of users	

It should to be noted that some indicators serve or inform diverse evaluation objectives, so there is high interrelation between the conclusions drawn for each point:

a. User acceptance of the uHSN

- ***Use of uHSN and content created:*** All user profiles participated in a balanced manner in the uHSN (not only direct care professionals, but also patients). **Figures 5-7** show that they used all functionalities of the uHSN during the assessment duration: patients personalized their profiles, messaged other users, participated in forums, shared materials and videos, and connected to video conferencing; some patients even managed groups. Remarkably, the patients were quite active and professionals interacted actively (mostly with the content associated with treatments and treatments prescription, which was available only for direct care professionals). Professionals messaged patients, monitored their progress, supported the platform, and checked users' usage: one of the most relevant activities was the uploading of therapeutic content as the initial database (for the special effort required to execute this task).

- ***uHSN accessibility and usability:*** The data we collected on the network access provider and time of day showed that the uHSN was used both from home and from outside the centers (there were a total of eight network providers); among other things (e.g., motivational issues), the data demonstrate that the uHSN was used without professional supervision. There was balanced distribution among all activity types (**Figure 8**): mainly medical activity (treatment prescription, 27%; treatments, 20%) and related to content (images, 18%; files, 14%). Although accessibility and usability were positively assessed with high scores in the intermediate iterations, both communities felt that specific steps in the interface could be improved, e.g., activities such as video uploading, in a more streamlined and direct manner. Nonetheless, the surveys, interviews, and focus groups revealed that the perception of usability

is very positive; we highlight this also because most respondents considered the uHSN design aesthetically pleasing.

- ***Effort needed to learn to use the uHSN:*** The surveys, interviews, and focus groups revealed that the Stroke community considered the learning process easy (65% patients and 60% professionals) vs. the Parkinson collective, which thought that this aspect could be improved upon (45% patients and 40% professionals). The triangulation of these results with **Figures 6-7**, and some interview answers, demonstrated autonomous and continuous use outside the centers (without any support from peers). We consider that this shows that learning was sufficient to allow users to use the platform.

- ***User attitudes towards uHSN and emergent issues:*** The surveys, interviews, and focus groups confirmed global positive outcomes of uHSN utility in professional management (80% satisfaction), with a high level of motivation achieved during the 6 months evaluation period. This is aligned with users notable efforts in content generation; uHSN use during non-working hours (**Figure 6**); and the discovery and execution of new, unforeseen utilities (as tools for new employees to socialize and learn from colleagues –*vide infra*).

- ***Access to the uHSN:*** To interpret these results properly, it is necessary to understand the projects' ecosystem. The platform was a new resource available to the professionals and they were using it voluntarily; their habitual work duties (mainly provide physical, cognitive, psychological therapies to patients) did not reduce and platform interaction had to happen outside working hours. **Figure 6** shows that there was high activity in evaluation period (February to July), especially in content creation during the first month. The visualization of the hourly access (**Figure 7**) together with users' feedback, indicates professional's' commitment with the platform use, as it shows that the uHSN was used throughout the day: traffic increased just before the centers opened and just before lunch time. **Figure 7** shows that, besides remote use, the uHSN was also used to complement the daily in-person activities, strengthening the traditional health processes in an interactive and online manner (the question was corroborated with users with professional profiles in the qualitative assessment).

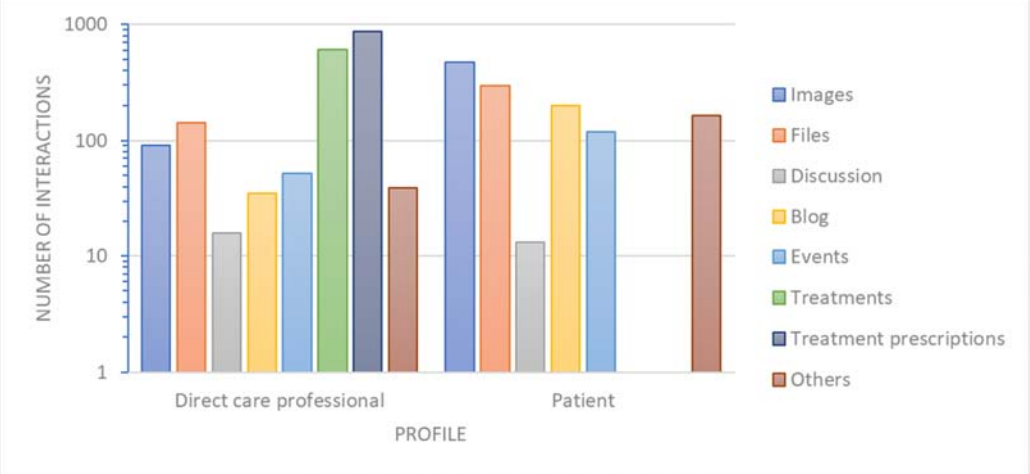


Figure 5. Type of content created by uHSN users

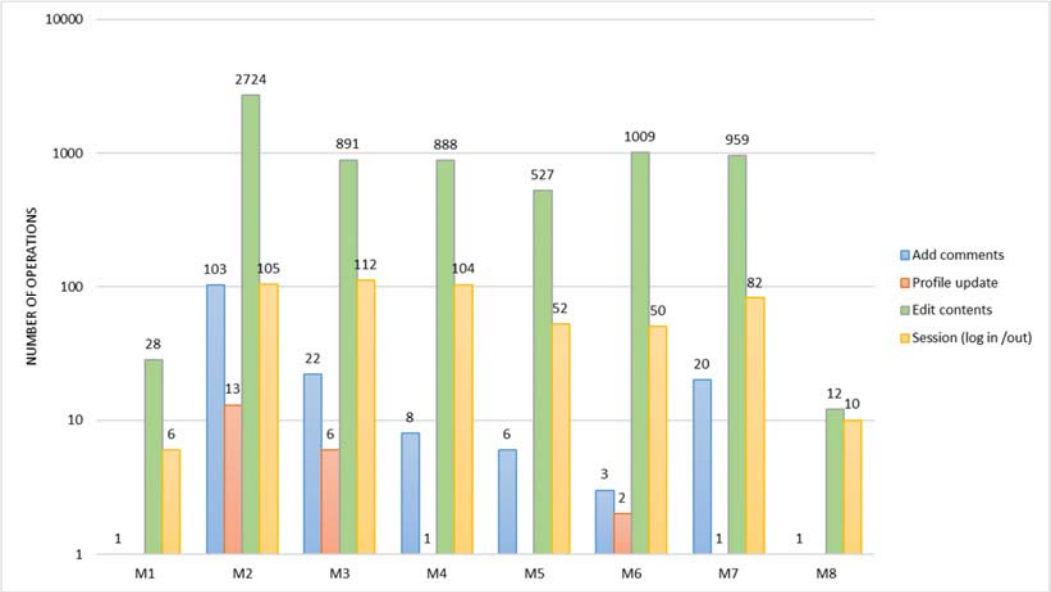


Figure 6. Monthly access to the uHSN based on content

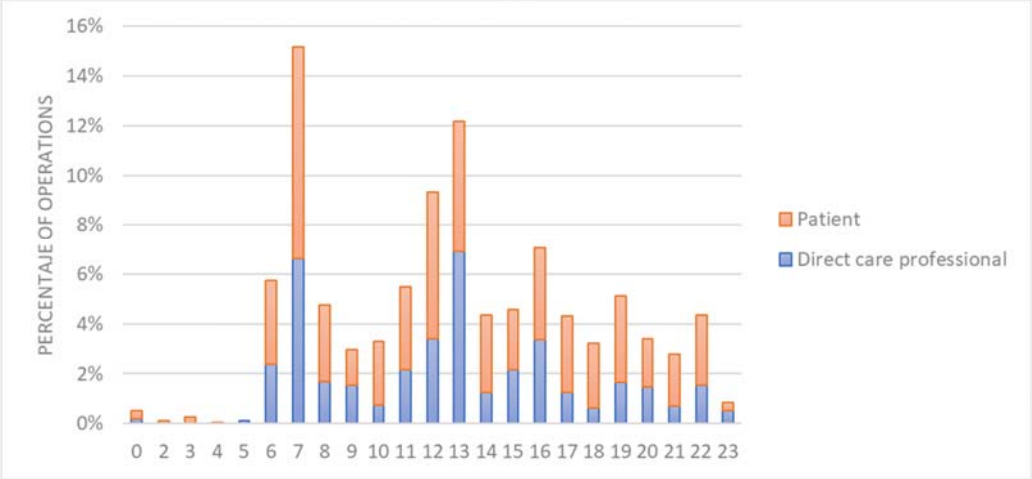


Figure 7. Hourly access to the uHSN based on user profile

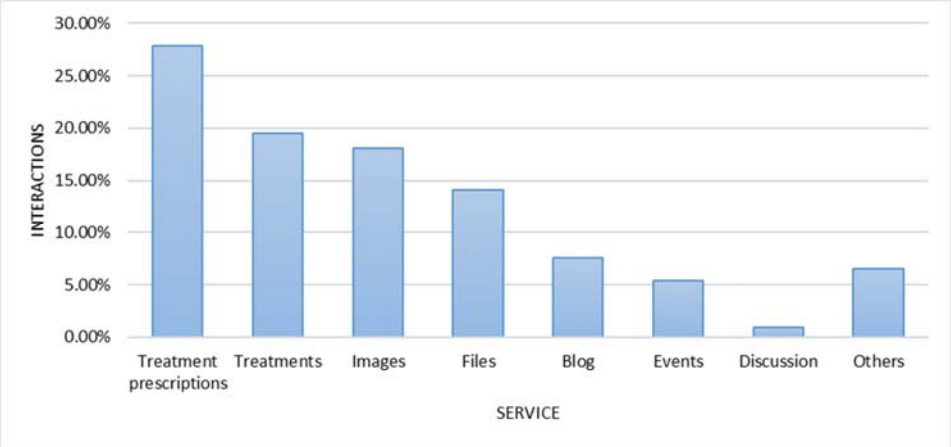


Figure 8. Content use on the uHSN

b. Productivity improvement

- ***User interaction through uHSN messaging:*** Data related to messaging (**Figure 9**) showed very active use: professionals sent 60% of messages (20% to patients and 40% among themselves) and patients interacted 40% through the uHSN (14% with professionals and 26% among themselves). Clearly, the uHSN users relied more on the content uploaded by the professionals, which achieved a greater level of interaction. Furthermore, the professionals were more interactive than patients: each professional (on average) reached 100% of users on both profile types and each patient reached 62.5% of users on both profiles types, which is drawn as the interaction ratio in the right axis in **Figure 9**.
- ***Use of paper:*** The surveys and interviews (both professionals and relatives) suggest the great potential of the uHSN for improving this indicator. During uHSN use, professionals estimated a 45% reduction in paper use: this would affect not only economic and ecological issues, but also the time devoted to generating and managing paper. The relatives complimented this idea, noting the convenience of being able to access information at a given moment without needing to rely on a caregiver's handwritten notes, of being able to be at home to receive letters, and the fact that information would not be lost.
- ***Administration time required to attend to staff issues:*** The interviews and focus groups showed very good predisposition of the administrative staff in adopting the uHSN as a daily framework. Success has to overcome the risk involved in the fact that communities may not have sufficient resources to address an organizational change in the service by and through the uHSN (staff have limited time to support, check, and develop platform). A very interesting aspect that emerged is that the professionals put into practice unexpected uHSN uses, using it also as a repository for classifying the information a carer must know when working at the center; a section of the uHSN was used as a welcome manual all employees were required to read: upon the arrival of a new employee, time was saved explaining the basics of the work and the center).
- ***Health professionals' time devoted to using the uHSN:*** As with staff, the results showed that health professionals had a very good predisposition in this regard. As stated earlier, and in general, change is a risk because it requires political transformation in communities, but unavoidably, these transformations shall be considered an investment and one of the most important aspects for capitalizing on the potential of the tool. For example, it was clearly reflected in the task of managing patient treatment, a very time-consuming task: all professionals highly valued (67% rated maximum score) the uHSN capacity for managing therapies, with options for programming multiple therapy assignations (e.g., one therapy for several patients; several therapies for one patient), thereby saving time and resources and improving productivity.

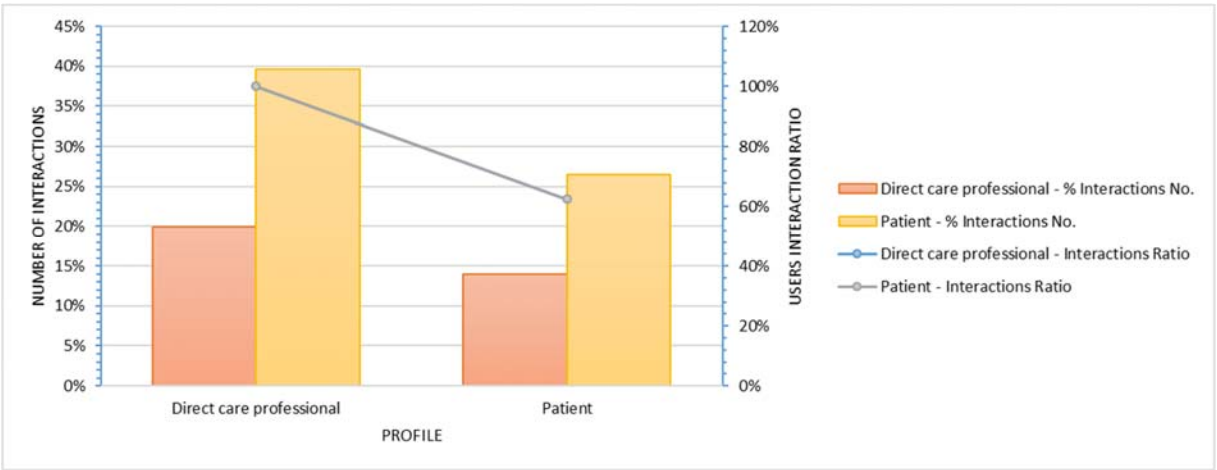


Figure 9. User interaction through uHSN messaging

c. QoS enhancement

- ***Improvement of communication among users, and new communication channels for the community:*** Messaging, discussion, and blog interaction logged by the uHSN (as supported by **Figures 5-7**) demonstrated that new communication channels were created and maintained through the uHSN. This was confirmed by all users in the surveys, interviews, and focus groups (100% of answers) acknowledging that the uHSN enhances personalized assistance and care (therapies, agendas, information), and recognizing its enormous communicative potential for follow-up intervention; one of the most important product values, together with fostering social relations, is remote social and emotional support.
- ***Improved patient medication management:*** The surveys, interviews, and focus groups (93% of answers) concluded that remote therapies imply a great effect, but professionals' implicit perceptions may drive the retaining and maintenance of direct intervention and care (face-to-face, non-verbal communication, personal feedback). For example, the professionals were prudent and cautious when evaluating possibilities for improving a patient's medication management and information that patients and relatives may have about the disease.
- ***Improved management of patient history:*** Patient follow-up is a key issue in recovery and disease control, and the professionals were clear about the utility of the uHSN in their professional management. The surveys, interviews, and focus groups (87% of answers) deemed the uHSN useful for improving the management of patient history and any patient information (and treatments, as seen in the previous section).
- ***Increased rate of remote therapies followed per patient:*** Patient perseverance and doing therapies at home is another key issue in recovery and disease control, and we verified that users accessed treatments from outside the centers (**Figures 5-7**). As revealed in the interviews and in **Figure 7**, patients accessed the uHSN before visiting the center, and the uHSN helped them exercise at home after the consultation. It should be taken into account that, as shown in the focus groups, new formats and languages are required for creating certain online therapeutic content (e.g., in the area of psychology, which is especially difficult), which can constitute interesting new lines of research. Of course, and as already mentioned, the tool is not meant to substitute face-to-face therapy, but to complement it.
- ***New discussion channels for preparing patient intervention:*** To date, professionals' discussion channels were mainly face to face meetings; evaluation revealed remarkable online inter-professional communication. Indeed, the number of interactions established among professionals was almost three times that of professional–patient interactions (**Figure 10**). As marked by the blue line (indexed as the interaction ratio in the right axis), each professional (on average) interacted with all the other professionals (100%) and with 79% of patients: this does not mean that 21% of patients were ignored, but that other professionals attended to them. Following this interaction ratio, each patient (on average) interacted with 82% of professionals and with 21% of patients. This was due to many of the relationships being established by replicating the typical structure of organizations, i.e., there are usually more patients than professionals (which led to every professional attending to, and relating with, several patients), and patients are often attended to by several professionals (which led to the establishment of additional relationships between these professionals). This was reinforced by 63% of the survey answers, showing the clear contribution of the uHSN in this scope.
- ***Emergent issues:*** The results showed very relevant scenarios in which direct attention is difficult, for example, delocalized patients or patients who cannot or do not want to visit the therapy centers due to emotional reasons. In these cases, the uHSN constitutes a big leap, not only in the quality of service but also in the access to therapy itself (from nothing to everything). Without losing sight of this clear contribution, it has to be taken into account that 55% of the interviewees recommended a progressive transition from direct to remote therapeutic assistance.

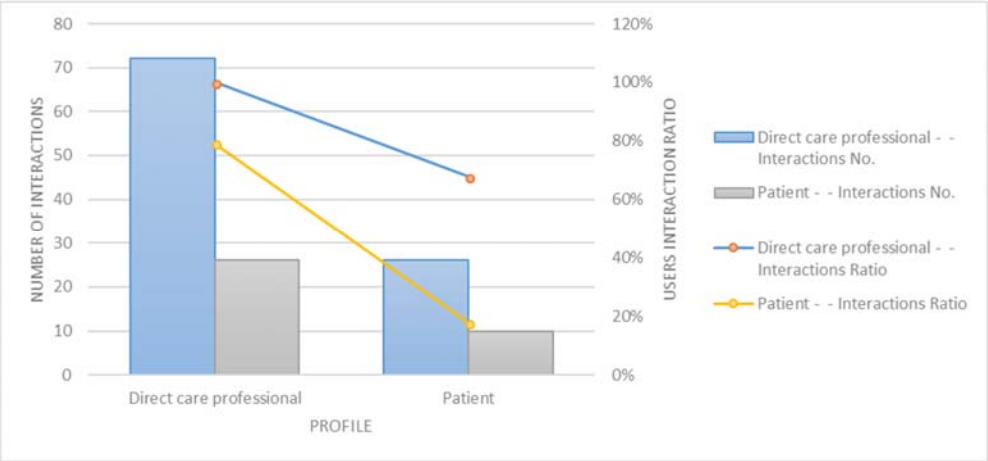


Figure 10. Community social activity

d. Fostering of social relations

- ***Community social activity (forums, groups, comments, etc.):*** The users participated in every type of relational flow, in order of relevance: "mixed" (e.g., therapists-patients, therapists-relatives), "professional" (e.g., therapist-therapist), and "external" (e.g., relatives-patients). Professionals were highly connected with each other and with patients, while patients are highly connected with professionals and less with each other (**Figure 10**). This is a good example of the need to improve the relational network of patients (by better defining patient profiles and patient groups) to increase their levels of interaction and improve their social relations.
- ***Enhancement of social circles (patient-professional, patient-patient, professional-professional):*** The surveys, interviews, and focus groups (together with "supporting therapeutic intervention") found that this is the uHSN's most useful feature. Patients and professionals agreed (90% both communities) that continued use of the uHSN enabled: (a) the creation of new communication channels between patients and health professionals; and (b) improvement in empathy, reciprocity, and affective companionship for assistance and disease care. The enhancement of social relationships affects the perceived empathy for living with disease and broadens social and personal circles to improve the perceived personalization assistance and confident care. Based on the evaluation experience, it should to be noted, as a recommendation for implementing the uHSN in other areas that professionals should plan on how to indirectly promote and involve non-professional users in the construction of their own social network, but avoid interfering as much as possible in this utility. Another option is limiting social relation external spaces to formal community activities and workshops.
- ***Emergent issues:*** Patients were concerned about the confidentiality, integrity, and provision of information in the uHSN, especially in forums and private messages (and also remote therapies by videoconferencing); thus, services associated with uHSNs have to bear in mind this preoccupation to inform the user adequately of data safety. In this sense, there were some worries about the challenge of finding a means of encouraging the construction of social communities and avoiding overlapping and redundant use with other OSNs. Thus, although it may seem obvious to designers and developers, as has been stated, teams must inform the user or client of the great difference between uHSNs and mainstream social networks. Another very interesting emerging issue already mentioned briefly is the fact that the professionals discovered and enjoyed unexpected uses of the uHSN outside the work to that allowed them to increase their social cohesion (organizing leisure activities common among peers) and integrate new partners (this is important, as there is a high replacement rate in the case of caregivers).

DISCUSSION

The new paradigm of uHSN offers a viable and open alternative to manage the support of patients and their wide context, that offers great developmental opportunities. The uHSN is thematic –related to a specific disease-; private and secure –restricted to the use of patients, relatives, and health professionals-; with specific objectives –around patient support-; small in size –from tens to hundreds of users-; supported by local therapeutic associations; capable of integrating innovative services –connection with sensors or interoperability with hospital information systems, among others-; based on predefined relationships governed by Network Groups; and designed through "Community" methodology. The research carried out has shown the capacity and future projection of the uHSN, especially to connect social and health worlds; to allow remote rehabilitation; to improve the efficiency of professionals; to strengthen or expand the patient's social environment; to improve the quality and immediacy of information; to promote social and emotional support among actors. In addition, the uHSN overcomes the main limitations of the social health networks that are described in the literature: quality, reliability, confidentiality and privacy.

Given the heterogeneity of the scenarios, assessment methodologies, and user profiles involved, it is complicated to address in a single paper all the results, implications, and interrelationships the evaluation has revealed. To make answering the question easier, this discussion is organized thematically, differentiating between technical and methodological arguments, and including the six areas recommended in the literature (as shown in **Table 1**) they refer to: privacy, security and transparency, validity assessment, design methodologies, system ecology, QoS, and technology enhancement.

Technical implications: Privacy, security and transparency, system ecology, QoS, and technology enhancement

In this context, some key questions are: Why uHSN? What is its added value? Why not capitalize on established OSNs? The results obtained from the proposed assessments answer these questions and conclude with the following strong points of uHSNs:

- Intensive possibilities of singularizing the flow and structure of social interactions, the virtualization and empowerment of patients' existing offline social networks, and the creation of new ones. The uHSN is sufficiently flexible to allow the creation of as many spaces as needed for every specific service requirement (e.g., the specific attendance of a single patient), confining the interactions related to that service into such a space and for the users accessing it. This led to a high level of connections and interaction ratios, as reflected in the results (inter-professional, 100%; professional–patient, 79%; 100% of positive survey answers).
- Predefined, known user roles and a sole administrator ensures the principles of therapeutic care: privacy, confidentiality, integrity, transparency, and provision of information.
- As the uHSN has a controlled and known number of users and a univocal objective, it is easy for the institution to ensure information quality and moderation, that is, it does not constitute a great burden of extra work for the institution.
- Personalized attention is highly valued, even indispensable, for users. The uHSN contributes to complementing the virtual and real worlds with 24/7 attention from therapists (online and in person). The results have distinguished this aspect with the high degree of access to the uHSN: for example, just before the centers are opened to the public and just before lunch time, as shown in **Figure 7**.
- The open and latest technology used allow the inclusion of innovative services, enhancing uHSN possibilities. We specifically implemented a responsive theme (that automatically adapts to mobile

phone, tablet, and computer) and a medication–effect tracking service that is the start-up page when a patient accesses the tool from a mobile device. Furthermore, we developed a module for receiving data (from monitoring devices such as Bluetooth wearables) and access to third-party data services (such as hospital information service through HL7 standards or e-learning content using SCORM standards).

However, achieving these strong points demands interesting discussions on the following aspects:

- *Design flexibility as a key response to an interactive and dynamic conceptualization of needs*. The interviews and mainly focus groups demonstrated that uHSNs for health communities present multiple and non-standard needs, as they require multiple and heterogeneous social networks. People sometimes have floating, emotional, and subjective expectations; seek familiarity and informal assistance; and value health care from an incalculable principle: confidence. Instead of the static conceptions of needs, we have to think in dynamic terms. Specific needs (user profiles) and common needs (shared by different groups and collectives) are transformed over the course of the disease and other general life circumstances. Needs also present changes when social interactions integrate new communicative spaces as OSNs. Dynamic needs are interactive needs, transversely emerging and constructing processes (new structures, organizations, interactions, identities and forms of communication) via negotiation and collaboration.
- *Integrating new virtual social existences with existing social organizations is essential*. Neither disease type nor patient age (or any individual characteristic) is a decisive factor; the assessments determined that the most important factor is how new virtual networks are created, taking into account preliminary and "real" social networks. Groups and institutions managing their activities without OSNs build their own background (health, culture, and social systems), which should be considered an entity with its own particularities and requirements. For example, fostering social relations is easier when they are carried out in small-scale health care associations (where previous social background builds closer relationships) instead of hospitals or other large institutions. Moreover, introducing other forms of interaction and communication, such as those performed in the uHSN as a complement to face-to-face therapy, as demonstrated in **Figures 5 to 7**, changes the entropic organization of social relations, adding new uses and forms of relationships. In conclusion, the assessment confirms that the format of the OSN is very important, and this includes how the OSN design is focused, how the user in their context is analyzed, and how the OSN concept is understood.
- *Individualizing and personalizing processes are essential in prospective and transferring terms*. Although these processes are complex, the focus groups revealed the uHSN as an analyzer of organizational dynamics, questioning current uses and defining a turning point that implies not well-defined risks. Currently, care providers usually spend a significant amount of time manually viewing and writing notes, some of them never read;[31] uHSNs can make it easier, e.g., notes available online in blog format allow commenting and facilitate reading in *down times*. However, the uHSN requires from professionals a new concept of time scheduling, demanding new health content (messages) and other forms of social mediation (media) adapted to new health care realities.

Methodological implications: Validity assessment, design methodologies, and system ecology

From a methodological perspective, and as a research strategy involving both health communities, CBRP was proven essential for meeting many key features of the uHSN:

- Using iterative cycles of evolution, each with design, implementation, and evaluation phases, allowed the final system to evolve considerably and target real user needs. Besides greater product maturity, we considered 60% more functionality in the last iteration than in the first.

- As expected,[32] participatory and action-oriented methodologies allowed patient-centered participatory solution design, which truly fitted what users needed, as demonstrated in the results obtained from the surveys, interviews, and mainly, focus groups.
- uHSN principles such as CBPR should acknowledge a community as an entity, and need to build on the strengths and resources within the community.[33] The qualitative evaluation showed that having a local entity providing existing real-world support enabled real involvement of end users that consider the system theirs, and not a third-party product. The qualitative interpretation was consistent with the quantitative results, which showed high activity from the first day. Additionally, it allowed the complementing and strengthening (not replacement or remaking) of current procedures, easing platform adoption.
- We used specific design methodologies to foster co-learning and capacity building among all project partners.[34] They allowed the creation of a common object world,[35] with unified objectives among all stakeholders (designers, developers, social workers, therapists); the empathy and compromise of the technical staff with the project; and better connections among needs (user), design (designer), and implementation (developer); in summary, a better final product.

Our methodology also emphasizes the continuous evaluation of the collaborative process throughout the development of an intervention. Qualitative and quantitative evaluation of the participatory design process help establish the principles and best practices for developing community-based systems for online support.[36-38]. Both considerations allow the reinforcement of validity assessment. CBPR and engineering design facilitate intersubjective analysis in tandem, exploring the meaning and significance of people, user profiles, and cultural healthcare constructions. Beyond controlled trials as an exclusive methodological approach, our vision is sensitive to interpersonal relationships, interpersonal communication, behavior changes for healthy lifestyles, and the impact of any change in professional intervention. Immersion in context renders it possible to understand local and singular situations in terms of result credibility (needs, perceptions, expectations), dependency, and consistency (comprehensive dimensions and helpful and illustrative indicators).[39]

CONCLUSIONS AND FURTHER RESEARCH

This paper contributes the design, development, and assessment of a new concept: the uHSN, defining two interaction areas ("backstage" and "onstage") and the design of a new transverse concept of "network spaces segments" that provides timely interaction among all involved profiles and that guarantees qualitative relationships.

As we have demonstrated, the uHSN overcomes the main limitations of traditional HSNs in the main areas recommended in the literature: privacy, security, transparency, system ecology, QoS, and technology enhancement. The research carried out with the proposed methodology contributes a complete, open, and modular platform that demonstrates its viability for use in all types of work areas; it also allows the scientific community to replicate the obtained results in very diverse environments with multidisciplinary professionals, and works in scenarios with ecosystems of heterogeneous user profiles.

From a methodological perspective, combining CBPR and engineering design methodologies proves its usefulness in health projects. The proposed assessment processes are focused as a social-based solution for supporting patients with chronic disease in two real-life health scenarios: a Parkinson patient association and a Stroke rehabilitation service in a hospital. As main conclusions, the qualitative and quantitative findings demonstrate the following key points:

- User acceptance of the uHSN, remarking not only on the viability, replicability, and future projection of uHSNs to connect health and social worlds, but also on the enhanced management of user profiles (patients, families, health professionals and carers).
- Improved productivity by optimizing efficiency, efficacy, and supporting distance rehabilitation, even with smart devices.
- QoS enhancement by guaranteeing privacy, confidentiality, integrity, transparency, and provision of truthful information to all user profiles.
- Fostered social relations by expanding users' social capital, improving quality and immediacy of information, and enhancing perceived peer/social/emotional support.

As further research, it is necessary to work on transferring the uHSN to each health community and conducting an internal follow-up to assess its future sustainability and to continuously improve the platform. Some alternatives are: new collaboration between health communities and companies or universities, integrating third-party systems for importing and creating new therapeutic content, attracting funds and grants for developing related products.

As a challenge, the scientific contributions of the present paper are the first step not only in customizing health solutions that empower patients, their families, and healthcare professionals, but also in transferring this new paradigm to other professional and social environments to create new opportunities.

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Competing interests. None.

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